

New Directions in Autism Research

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Autism –
 A neurodevelopmental disorder
 affecting social behavior and
 communication

Overview of today's talk

- Prevalence of ASD
- Causes – genetic and environmental factors
- Diagnosis and screening
- Treatment approaches
 - Early intervention
 - Medical conditions
 - School age children
 - Adolescents and adults
- Leave time for questions (hopefully!)

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Autism

The Public Health Challenge

Prevalence – ASD: 1 in 110

– Type 1 Diabetes: 1 in 400

– Childhood Cancer: 1 in 2000

– Cystic Fibrosis: 1 in 3500

This year, more children will be diagnosed with ASD than AIDS, diabetes, and cancer combined

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Measuring the Public Health Challenge

World Health Organization "Burden of Disease"

- | | | |
|---|---|---------------------------------|
| <ul style="list-style-type: none"> ▪ Prevalence ▪ Functional impairment ▪ Chronicity ▪ Age of Onset ▪ Cost | } | "Disability Adjusted Life Year" |
|---|---|---------------------------------|

➔ Autism > Type 1 Diabetes, Childhood leukemia, CF
 Costs to society in US: approx. \$35B/yr

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Health care experience and family impact

Kogan et al., 2008, *Pediatrics*

Compared to other children with special health care needs, children with ASD are:

- More likely to have unmet needs for health care and family support services
- Difficulty receiving coordinated care and appropriate referrals
- Families have more financial problems and large out-of-pocket expenses
- Parents more likely to reduce or stop work to care for child

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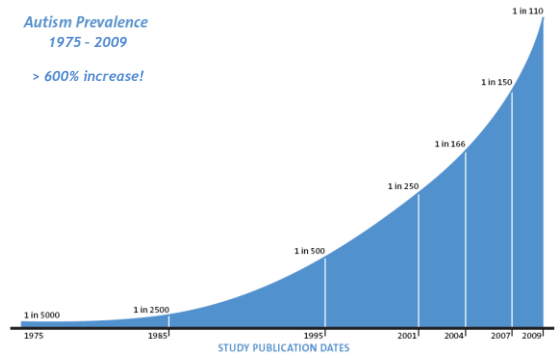
Challenges in early diagnosis

- American Academy of Pediatrics recommends ASD screening for all children at 18 and 24 months (Johnson et al., 2007)
- Yet, average age of diagnosis is 53 months (ADDM, 2009) or even later (Shattock et al., 2009)
- Children who are Black, Hispanic, or other non-White ethnicities are less likely to receive a diagnosis (Mandell et al., 2009)

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Autism Prevalence 1975 - 2009

> 600% increase!



25% of the increase due to diagnostic change from mental retardation to ASD

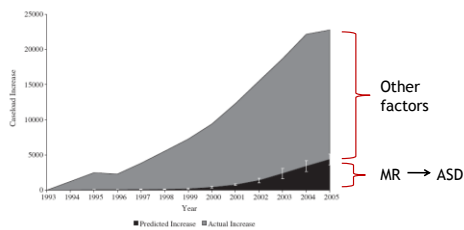


Figure 4 Autism caseload increase in California between 1992 and 2005. Shaded in grey is the observed increase in DDS autism cases. In black is the proportion of that increase that is due to diagnostic change. 95% CIs are denoted by white bars

From King and Bearman, *International J. of Epidemiology*, 2009

Changes in prevalence rates for ASD versus Mental Retardation

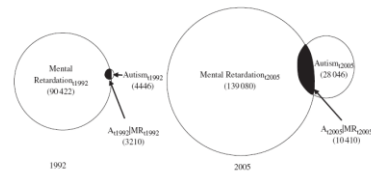


Figure 3 The changing diagnostic world in California between 1992 and 2005. The number of cases of autism and MR both expand, though the proportion of autism cases is increasing at a much greater rate. As this is happening, the rate of co-morbidity within the autism population is decreasing, though the number of co-morbid cases is increasing, as is co-morbidity within the population with MR. Represented in the non-shaded portion of the MR circles is MR, the number of cases of MR without co-morbidity

From King and Bearman, *International J. of Epidemiology*, 2009

Recent study finds that proportion of children with ASD with IQ ≥ 70 is close to 60 %

2009 CDC prevalence study

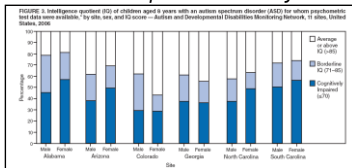


FIGURE 3 Intelligence quotient (IQ) of children aged 6 years with an autism spectrum disorder (ASD) for select psychometric test data were available, by site, sex, and IQ score—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2008



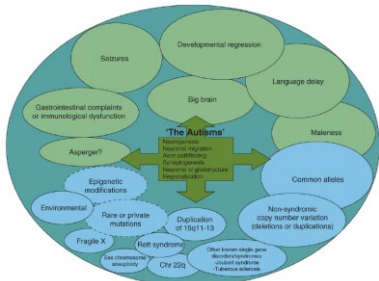
Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, United States, 2008

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What do we know about the causes of autism?

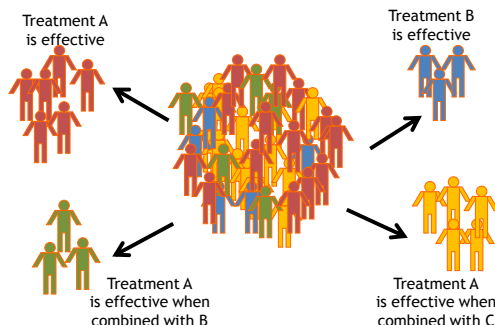
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“The Autisms”
Multiple conditions with multiple etiologies



Autism spectrum disorders: developmental disconnection syndromes
Daniel H Geschwind¹ and Pat Levitt *Current Opinion in Neurobiology* 2007, 17:103-111

Which treatments are most effective for which people? Need to define subtypes of ASD



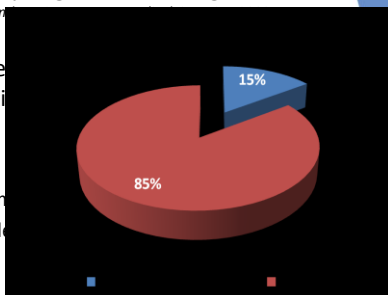
Multiple genetic etiologies

Lintas, C et al

~ 10-15% - identified genetic etiologies

Examples:

- Fragile X
- Neurofibromin
- Tuberous sclerosis

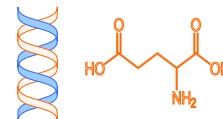


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A complex interaction among genetic and environmental factors contribute to risk for ASD

Protective factors

- Folic acid
- Female gender



Risk factors

- Parental age
- Prematurity
- Maternal infection
- Maternal antibodies
- Organophosphate pesticides

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Strategies for discovering genetic and environmental risk factors for autism

Prospective study of genetic and environmental risk factors for autism in high-risk siblings



Craig Newschaffer, Ph.D.
Drexel University



Joe Piven, M.D.
UNC Chapel Hill

- Seven universities collaborating
- 1700 infants studied prospectively (1000 from conception)
- 500 infants will have detailed brain imaging data
- DNA and environmental exposure data collected
- Funding: NIH, Autism Speaks, Simons Foundation

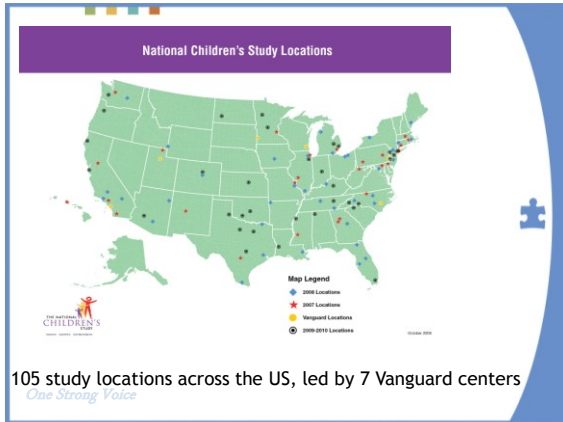
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Strategies for discovering genetic and environmental risk factors for autism

National Children's Study

- Funded by the NIH
- Largest long term study of impact of genetic and environmental factors on children's health outcomes to date
- 100,000 children and their families followed longitudinally from conception through adulthood
- Approximately 1,000 children will be diagnosed with ASD
- Unprecedented opportunity to study risk factors for ASD





What is being studied?

- natural and man-made environmental factors
- biological and chemical factors
- physical surroundings and geographic locations
- genetics
- social, cultural and family influences



New Directions in Diagnosis and Treatment

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2007 American Academy of Pediatrics

Recommendations to pediatricians:

- Recognize the signs and symptoms of autism
- Administer ASD screening tool at 18 and 24 mo visit
- Offer educational, community, and medical subspecialty resources



Screening Tools for Infants and Toddlers

- First Year Inventory
 - Parent questionnaire
 - Assesses behaviors in 12 month olds
- M-CHAT
 - Parent questionnaire combined with follow-up phone call
 - Assesses behaviors in 18-24 month olds

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Examples of FYI questions

- Does your baby turn to look when you call your baby's name?
- What do you typically have to do to get your baby to smile or laugh at you?
- Does your baby babble?
- Does your baby seem overly sensitive to your touch?
- Are your baby's sleeping and waking patterns regular from day to day?
- Is it difficult to calm your baby once he or she is upset?
- Is your baby content to play along for an hour or more at a time?

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Diagnostic and assessment tools for infants and toddlers with ASD

- Autism Diagnostic Observation Schedule: Toddlers Module (< 30 mos)
- Autism Observation Scale for Infants (6-24 mos)

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Proposed changes to Diagnostic Manual (DSM-V)

AMERICAN PSYCHIATRIC ASSOCIATION

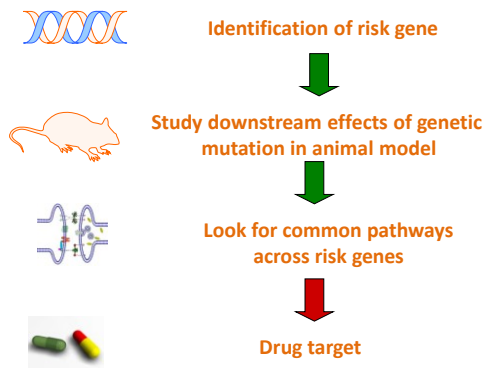
- Pervasive Developmental Disorders replaced with "Autism Spectrum Disorders" (ASD)
 - A single spectrum with no subtypes of Asperger syndrome, Childhood Disintegrative Disorder, and PDDNOS
 - Separation among subtypes is not reliable and not correlated with differences in causes or treatment approaches
- Instead of three types of symptoms (social, communicative, repetitive behaviors), only two types (social communication, repetitive behaviors)
- Symptom severity for ASD defined along a continuum from subclinical symptoms to severe

New directions in the treatment of ASD

How do we translate complex genetic findings into effective biomedical treatments?

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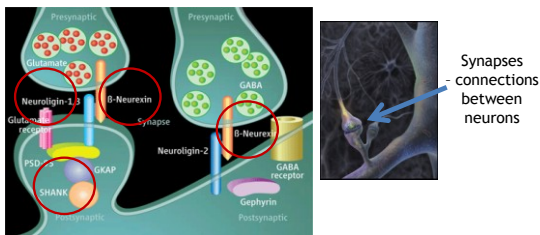
Translating genetic findings into clinically useful tools: Drug discovery



NEUROSCIENCE 13 JULY 2007 VOL 317 SCIENCE

Autism's Cause May Reside in Abnormalities at the Synapse

New genetic evidence is leading researchers to home in on the cleft separating neurons as the site where the disorder may originate



Examples of studies of new drugs targeting the synapse

Condition	Gene	Mechanism	Drug	Results	Researchers
Fragile X	FMRP on X Chrom	Glutamate receptors leading to hyper-excitation	Lithium Fenobam Baclofen	Promising; Clinical trials with FraX and ASD patients underway	Mark Bear Randi Hagerman Jeffrey Conn
Tuberous Sclerosis Complex	TSC1 or TSC2	mTOR signaling	Rampamycin	Animal studies show improvements in memory and learning and shrinking of tumors; clinical trials promising	Alcino Silva
Neurofibromatosis	NF1 gene	Enhancement of GABA release leading to hyper-excitation	Statins	Clinical trial showed some improvement in patients	Alcino Silva

Other promising directions in treatment of ASD

- Treatment of medical conditions associated with ASD
- Early intervention in infants and toddlers
- Interventions for older children and adults

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Treatment of medical conditions associate with ASD¹

- Sleep problems – 52-73%
- Seizures and epilepsy – 5-49%
- GI problems – 8-59%
- Food sensitivity – 30-90%
- Anxiety – 43-84%
- Depression – 2-30%

Significant impact on quality of life for Individuals with ASD and their families

Many times go unrecognized and untreated

Can contribute to behavioral challenges and impair ability to fully benefit from educational interventions

¹ Levy, Mandell, and Schultz (2009) *Lancet*

Autism Treatment Network

Funded by Autism Speaks and the Health Resources and Services Administration

- Address the medical issues that individuals with autism face
- Provide comprehensive, state-of-the-art, coordinated medical care
- Develop standards of care
- Enhance communication among providers
- Provide training for physicians and other clinicians

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Autism Treatment Network

- Fourteen medical centers participating
- Patient registry of ~2000 children and adolescents
- Over 100 physicians serve on subspecialty committees in the areas of sleep, GI, pediatrics, psychiatry, neurology, genetics, metabolics, psychology and speech pathology
- Provide training across the US through community-based and telemedicine programs
- Competed successfully for \$12M in federal funding to support research, guideline development, and dissemination
- Conducting 10 clinical research studies on nutrition, sleep, GI, metabolic deficiencies, bone density and psychiatric co-morbidities

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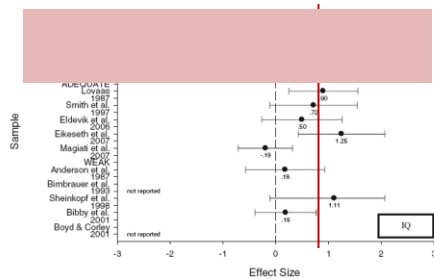
Early intervention

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Traditional ABA approaches with preschool age children

Comprehensive Synthesis of Early Intensive Behavioral Interventions for Young Children with Autism Based on the UCLA Young Autism Project Model

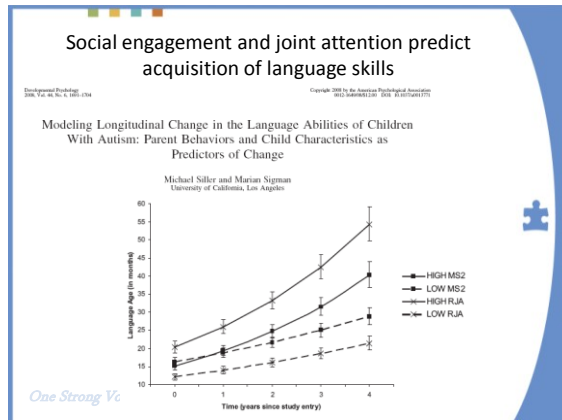
Brian Reichow - Mark Wolkow J Autism Dev Disord 2008



IQ

New directions with toddlers: Developmental intervention approaches

- Built on science of developmental psychology rather than learning theory from applied behavior analysis
- Children learn about their world through active exploration
- Children are active learners who form and test hypotheses about the world – “intuitive statisticians”
- More complex skills are built on earlier ones in developmental sequence
- Learning occurs in the context of affectively rich social relationships



Developmental intervention approaches

- Kasari et al – joint attention intervention
- Prizant and Wetherby - SCERTS model
- Rogers and Dawson – Early Start Denver Model

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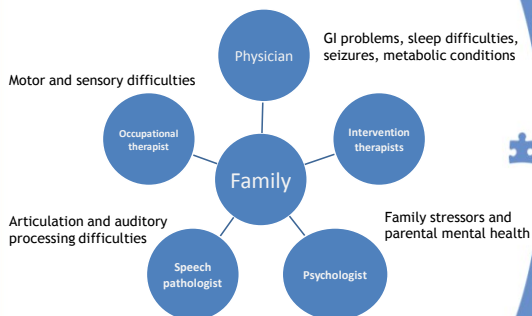


Early Start Denver Model

- Developed by Rogers and Dawson
- Comprehensive intervention program and curriculum
- Integrates developmental and behavioral approaches
- Appropriate for children as young as 12 months through preschool age

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Interdisciplinary team: Meeting the complex needs of children with ASD



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PEDIATRICS

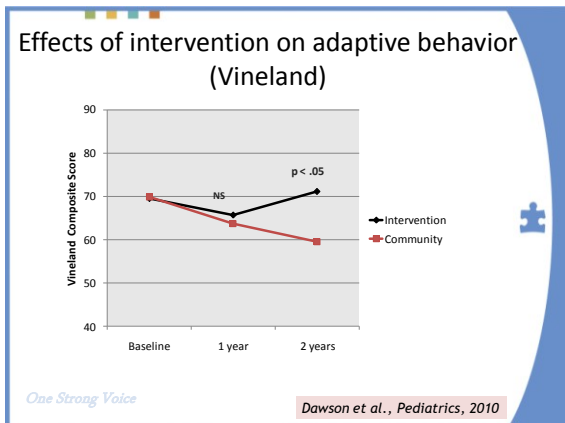
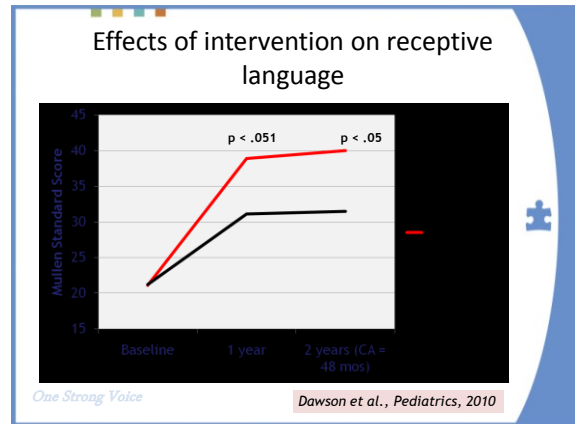
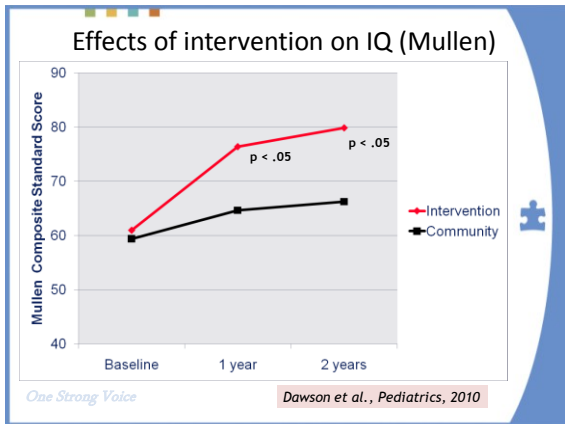
Volume 125, Number 1, January 2010

Randomized, Controlled Trial of an Intervention for Toddlers With Autism: The Early Start Denver Model

Geraldine Dawson, Sally Rogers, Jeffrey Munson, Milani Smith, Jamie Winter, Jessica Greenson, Amy Donaldson and Jennifer Varley

- Funded by National Institutes of Health
- Conducted at University of Washington
- Dawson, PI in collaboration with Sally Rogers, UC Davis
- All children < 2.5 years of age when intervention began
- Randomized study
- 2 year intervention – 25 hours per week (20 therapist-delivered, 5 parent-delivered)

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Changes in diagnosis

Group	PDD → Autism (worsened)	Autism → PDD (improved)
Community	23.8%	4.8%
ESDM	8.3%	29.2%

p < .05

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Early Start Denver Model

Pre-intervention

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Early Start Denver Model

After 6 months

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Autism Speaks Toddler Treatment Network

Institution	PI
Univ. of N. Carolina	Grace Baranek, Ph.D.
Dalhousie University	Susan Bryson, Ph.D.
Univ. of Massachusetts	Alice Carter, Ph.D.
Univ. of California, Davis	Sally Rogers, Ph.D.
Univ. of Northern Colorado	Hanna Schertz, Ph.D.
UCLA	Connie Kasari, Ph.D.
Florida State University	Amy Wetherby, Ph.D.

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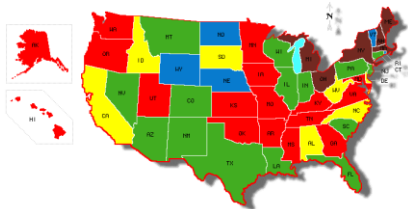
Common components of infant-toddler interventions for ASD

- Parent coaching
- Individualized activities designed to meet the developmental needs of each child
- Increase parental responsiveness to infant cues
- Specific skills targeted
 - Social communication
 - Nonverbal communication
 - Joint attention
 - Positive affect

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Fighting for the right to early intervention: Ending insurance discrimination



- 18 states have autism insurance reform
- 28+ states have active bills in development

Older children and adults with autism spectrum disorder

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Some common challenges

- Language and communication
- Anxiety (also, ADHD and depression)
- Social skills
- Transition from adolescence to adulthood

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Language and communication

- Important – some children develop spoken language for the first time during middle childhood
- New learning occurs throughout the lifespan
- New approaches to augmentative communication
 - iPrompts – picture based application for the iPhone, iPod Touch and iPad
 - Proloquo2go – touch icons that voice comments and questions

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Anxiety

- Jeff Wood and colleagues at UCLA
- Used cognitive behavioral therapy (CBT) augmented to address social and adaptive behavior deficits that can contribute to anxiety
- 78.5% of the children in the clinical trial improved
- Several books discuss use of CBT with adolescents and adults with ASD

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Social skills training

- Social skill training for children, adolescents, and adults with ASD is effective if implemented in real-world settings, such as the classroom and social groups
- Frankel and colleagues (UCLA) – Children's Friendship Training
 - Manualized, parent-assisted intervention in 2nd – 5th graders
 - Targets conversational skills, peer entry, friendships, sportsmanship, play dates, and handling teasing
 - 87% of the children showed improvement
- Recent review of 66 studies found two interventions had strong empirical evidence for efficacy
 - Social skills groups
 - Video modeling of social skills

Transition to adulthood

> 800,000 children with ASD will be entering adulthood

Of the \$35B spent annually for autism care, most is for adult services

Important topics include

- Adult ASD diagnosis and prevalence
- Community integration and transition models
- Psychiatric and medical co-morbidities
- Successful employment and well-being
- Aging

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Transition to adulthood

Three simple principles:

- (1) Start early
- (2) Involve all service agencies and funding agencies
- (3) Try to have work secured before graduation or identify postsecondary education option before graduation occurs

Key issues:

- Housing
- Job training
- Social skills training
- Estate planning

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Common health challenges of adulthood

- Epilepsy
- Accidents
- Obesity
- Psychiatric conditions, such as anxiety
- Heart-related conditions

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For more information on Autism Speaks Advancing Future for Adults with Autism Initiative, visit <http://www.afaa-us.org>





www.afa-us.org

How do we as a society, help people with autism achieve their goals and become participating members of society?

Some new ideas:

- Think Tanks/Expert Panels - identifying effective programs and addressing state by state challenges
- National Town Hall Meeting - for all who are affected to voice their concerns and hopes for the future
- An Autism Congress which will develop a comprehensive overview and make recommendations to federal and local government.

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www.autismatwork.org

IMAGINE HAVING AN EMPLOYEE WHO...

- Is always on time
- Doesn't gossip
- Follows your exact orders
- Never lies
- Doesn't steal (not even a pen)
- Pays attention to detail
- Is persistent
- Is dependable and rarely absent
- Is loyal to the company
- Is dedicated to getting the job done
- Enjoys repetitive activities
- AND ... is grateful to have the job!

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http://www.autismspeaks.org/community/family_services/autism_in_the_workplace.php

- Highlights individuals in the Miami/Dade County who have found jobs which suit their extraordinary abilities
- Program in Nassau/Suffolk County
- Jay Nolan Services in Los Angeles
- Provides Link to Resources
- Newsworthy items
- Information for Employers

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Other resources on the Autism Speaks' Website

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ASD Video Glossary

Click to see video glossary:

<http://www.autismspeaks.org/video/glossary.php>

- The Interactive ASD video glossary is a web-based tool to help parents and teachers better understand developmental milestones and abnormal behaviors as a result of autism
- It is freely distributed on the AS website as well as on video to educators, parents, childcare providers and physicians
- It shows age-normal behaviors and also demonstrates examples of subtle differences in children with and without ASD

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First 100 Days Kit


A tool kit to assist families in getting the critical information they need in the first 100 days after an autism diagnosis.

http://www.autismspeaks.org/community/family_services/100_day_kit.php

Now in Spanish!

- About Autism
 - Why was my child diagnosed?
- Your Family and autism
 - How does my family adjust?
- Getting Your Child Services
 - Early Intervention and legal rights
- Treating Autism
 - Some beneficial therapies
 - Tracking kits
- Making it Happen
 - Assembling a medical team
- What to do in an emergency

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AUTISM SPEAKS™

Asperger Syndrome and High Functioning Autism


Tool Kit

A tool kit to assist families in getting the critical information they need in the first 100 days after an Asperger Syndrome or High Functioning Autism diagnosis.

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http://www.autismspeaks.org/community/family_services/school_kit.php



- What is autism?
- How might a child with special needs be a part of our school? - *specific examples*
- General Strategies for Intervention - *what communication can be supported? What strategies can be used to improve social behavior?*
- For specific members of the School Community - *bus drivers, custodial staff, office staff, school nurses*
- Resources - *books, DVDs, other*


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http://www.autismspeaks.org/whatisit/talking_to_parents_action_kit.php

- As an early childhood educator, you are face-to-face with young children every day. You observe them, teach them, love them and interact with them. That means you're in the *ideal position* to notice if their development seems delayed.
- When this happens — **you need to talk to the parents and urge them to have their child screened.**
- There is no doubt that this can be a difficult conversation to have with a parent. But through this program, you'll have the **tools and conversation-starters** you need to speak up when you suspect autism.
- The tool kit can start the conversation

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<http://www.autismspeaks.org/community/resources/>

North Carolina: <http://www.autismspeaks.org/community/fsdb/state.php?sid=38>

- Where to Get an Autism Diagnosis
- Early Intervention
- Preschool
- Adult
- Advocacy, Legal resources
- Community and Network Support
- Interventions
- Biomedical Interventions
- Health Professionals
- Services

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[Autism Safety Searchable Resource Website](#)

First Responders
The Autism Safety Project provides First Responders with information and guidelines for communicating with individuals with Autism Spectrum Disorder (ASD) in emergency situations.

Individuals with ASD: Response to Emergencies
"If you've met one person with autism - you've met one person with autism." Stephen Shore
Autism manifests itself differently in each individual with ASD, varying in severity and symptoms. While there are often common behaviors across the autism spectrum, there is no single one that is always typical of an individual with ASD. This can make it difficult for a safety professional to react accordingly, which is critical for both a successful interaction and the safety of these individuals.
Information on Autism Spectrum Disorder - [Print Version of Autism Basics PDF](#)

First Responders Training
The overall goal of First Responder Training is to ensure the safety of ALL involved in an emergency situation. Important points to include when training First Responders are:
- Identification of medical and behavioral risks associated with individuals with ASD
- Options for risk management
- Common Characteristics of individuals with ASD

Click [here](#) to go to the Autism Speaks Community Connections' First Responders page!

A Collaborative Effort: Families and First Responders
The Autism Safety Project supports family participation in order to ensure that the most effective and safe responses to emergency situations are provided to individuals with ASD.

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Autism Speaks Social Networks

autismspeaksnetwork.ning.com

- forums
- groups
- facebook
- blogs
- new ideas
- post videos

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